



**BILLING CODE: 4163-18-P**

**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**Centers for Disease Control and Prevention**

**[60Day-18-1092; Docket No. CDC-2018-0095]**

**Proposed Data Collection Submitted for Public Comment and  
Recommendations**

**AGENCY:** Centers for Disease Control and Prevention (CDC),  
Department of Health and Human Services (HHS)

**ACTION:** Notice with comment period

**SUMMARY:** The Centers for Disease Control and Prevention (CDC), as part of its continuing effort to reduce public burden and maximize the utility of government information, invites the general public and other Federal agencies the opportunity to comment on a proposed and/or continuing information collection, as required by the Paperwork Reduction Act of 1995. This notice invites comment on a proposed information collection project titled "Sudden Death in the Young (SDY) Case Registry". The goal of the SDY Case Registry is to compile standardized data on sudden and unexpected deaths among infants, children, and young

adults, which are not explained by homicides, suicides, overdoses, or the result of an external cause that was the only and obvious reason for the fatal injury, or terminal illnesses.

**DATES:** CDC must receive written comments on or before [INSERT DATE 60 DAYS AFTER PUBLICATION DATE IN THE FEDERAL REGISTER].

**ADDRESSES:** You may submit comments, identified by Docket No. CDC-2018-0095 by any of the following methods:

- Federal eRulemaking Portal: Regulations.gov. Follow the instructions for submitting comments.
- Mail: Jeffrey Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, N.E., MS-D74, Atlanta, Georgia 30329.

**Instructions:** All submissions received must include the agency name and Docket Number. CDC will post, without change, all relevant comments to Regulations.gov.

Please note: Submit all comments through the Federal eRulemaking portal (regulations.gov) or by U.S. mail to the address listed above.

**FOR FURTHER INFORMATION:** To request more information on the proposed project or to obtain a copy of the information collection plan and instruments, contact Jeffrey Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, N.E., MS-D74, Atlanta, Georgia 30329; phone: 404-639-7570; E-mail: [omb@cdc.gov](mailto:omb@cdc.gov).

**SUPPLEMENTARY INFORMATION:**

Under the Paperwork Reduction Act of 1995 (PRA) (44 U.S.C. 3501-3520), Federal agencies must obtain approval from the Office of Management and Budget (OMB) for each collection of information they conduct or sponsor. In addition, the PRA also requires Federal agencies to provide a 60-day notice in the Federal Register concerning each proposed collection of information, including each new proposed collection, each proposed extension of existing collection of information, and each reinstatement of previously approved information collection before submitting the collection to the OMB for approval. To comply with this requirement, we are publishing this notice of a proposed data collection as described below.

The OMB is particularly interested in comments that will help:

1. Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility;
2. Evaluate the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;
3. Enhance the quality, utility, and clarity of the information to be collected; and
4. Minimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g., permitting electronic submissions of responses.
5. Assess information collection costs.

#### Proposed Project

Sudden Death in the Young Registry - Revision - National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)  
Centers for Disease Control and Prevention (CDC).

## Background and Brief Description

Sudden Death in the Young (SDY) is defined as a sudden and unexpected death among an infant, child, or young adults (up to age 20), which is not explained by homicide, suicide, overdose, or the result of an external cause that was the only and obvious reason for the fatal injury, or terminal illnesses. Injury deaths where there may have been an initiating natural cause (e.g., drowning or death of the driver in a motor vehicle accident, which may have been triggered by an underlying cardiac or neurological condition) are also included in the definition.

SDY deaths are not systematically monitored and estimates of the annual incidence of SDY vary due to differences in definitions, inconsistencies in classifying cause, variable age and study populations, and differing case ascertainment methodologies. Because standardized information has not been collected on the incidence, causes, and risk factors, developing evidence-based prevention measures has been challenging.

To address these gaps, CDC, in collaboration with the National Heart, Lung, and Blood Institute and the National Institute of Neurological Disorders and Stroke at the National Institutes of Health implemented the SDY Case Registry in 2015. Standardized data collected through the SDY Case Registry has been used by the NIH and CDC awardees to generate estimates of the incidence of SDY; to elucidate risk factors; and to develop

evidence-based prevention strategies for SDY. The SDY Registry also creates infrastructure for future research about previously unknown or unrecognized risk factors for, and causes of, these deaths.

This information collection request is to continue the SDY Registry. By continuing the prior work of the SDY Registry, the information collected under this request will allow CDC to provide technical assistance to awardees so they can improve their jurisdiction's information on SDY. This includes two additions to their routine Child Death Review (CDR) program: 1) entering SDY information from existing data sources (e.g., medical records, autopsy reports) used during CDR review into the established web-based NCFRP Case Reporting System; and 2) convening clinicians with three different types of expertise (pediatric cardiology; pediatric neurology or epileptology; and forensic pathology) to conduct advanced clinical reviews of a subset of SDY cases to allow for a more thorough review of information compiled and to generate additional data about the classification of the death. The intended result will be data that can establish incidence and guide program and policy decisions at the state/jurisdiction and local levels.

CDC estimates that the participating states/jurisdictions will collect data on approximately 739 SDY cases per year. For participating states/jurisdictions, burden is estimated for

reporting required case information. Based on historical program information, it is estimated that approximately half (370) of the 739 estimated SDY cases each year will undergo an advanced clinical review and classification of cause by a team of three medical experts.

OMB approval is requested for three years. The total estimated annual burden is 521 hours. There are no costs to respondents other than their time.

Estimated Annualized Burden Hours

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
State Health Personnel	SDY Module I	14	53	10/60	124
Medical Experts	Advanced Review	42	26	15/60	273
State Health Personnel	SDY Module N	14	53	10/60	124
Total					521

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